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Aboriginal and Torres Strait Islander lead and governed research: A sign of social change

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Aboriginal and Torres Strait Islander lead and governed research: A sign of social change

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Abstract

There has been a long history of research conducted on Aboriginal and Torres Strait Islander peoples. Linda Tuhiwai Smith (1999:3) makes the statement that she has heard that “we [Indigenous peoples] are the most researched people in the world”. Historically, the vast majority of this research has been carried out by non-Indigenous people. Over the years some of this research has been undertaken without permission and without regard to Aboriginal and Torres Strait Islander peoples’ rights. At times communities have not been aware that non-Indigenous people were undertaking research while within their communities. There has been a plethora of reports, books, articles and theses generated. Aboriginal and Torres Strait Islander peoples have a wealth of experience and knowledge about research.

It is this collective experience and knowledge that informs the newly established, and NH&MRC funded Centre for Clinical Research Excellence (CCRE). This CCRE is being lead and governed by the Queensland Aboriginal and Islander Health Council (QAIHC). QAIHC is the State peak body for Aboriginal and Torres Strait Islander Community Controlled Health Services in Queensland. The CCRE is a partnership between QAIHC and the Queensland University of Technology, the University of Queensland, James Cook University, the National Heart Foundation, and the University of Wollongong. The establishment of the CCRE under the Community Controlled model of governance is unique and presents both opportunities and challenges for innovative partnerships between universities and Aboriginal and Torres Strait Islander community organisations and stands in direct opposition to the research of the past.

Keywords: Aboriginal; Torres Strait Islander; Indigenous; Community Controlled; CCRE; Health

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Introduction

Aboriginal and Torres Strait Islander peoples have a wealth of knowledge and experience about research based on a long history of research conducted on Aboriginal and Torres Strait Islander peoples. Over the years some of this research has been undertaken without permission and without regard to Aboriginal and Torres Strait Islander peoples' rights (Cruse, 2003). At times communities have not been aware that non-Indigenous people were undertaking research while within their communities. There has been a plethora of reports, books, articles and theses generated (Gilbert in Roberts 1995). It is this collective experience and knowledge that informs the newly established, and NHMRC funded Centre for Clinical Research Excellence (CCRE).

This NHMRC CCRE is being lead and governed by the Queensland Aboriginal and Islander Health Council (QAIHC). QAIHC is the State peak body for Aboriginal and Torres Strait Islander Community Controlled Health Services in Queensland. This NHMRC CCRE is a partnership between QAIHC and the Queensland University of Technology (QUT), the University of Queensland (UQ), James Cook University (JCU), the National Heart Foundation (NHF), and the University of Wollongong (UoW) as well as four participating health services. These include: Townsville Aboriginal and Islander Health Service (TAIHS), Inala Indigenous Health Service, Kambu Medical Service (Kambu), Brisbane Aboriginal and Islander Community Health Service (Brisbane AICHS). The establishment of a CCRE under the Community Controlled model of governance is unique and presents both opportunities and challenges for innovative partnerships between universities and Aboriginal and Torres Strait Islander community organisations and stands in direct opposition to the research of the past. The CCRE model is reframing Aboriginal and Torres Strait Islander research experiences and extending the principle of community control within the research domain. This paper will outline the model employed by this NHMRC CCRE and the methods and strategies it proposes to utilise in transforming Aboriginal and Torres Strait Islander health research.

Research undertaken in the Past

There has been a long history of research conducted on Aboriginal and Torres Strait Islander peoples (Dodson, 1995; Huggins, 1998; Martin, 2001; Rigney, 2001). Historically, the vast majority of this research has been carried out by *non*-Indigenous people. The research experience as one of the most researched groups has historically also been exploitative with little of value being accrued by Aboriginal and Torres Strait Islander people or their communities (ARI, 1993: 2). Over the years some research has been undertaken without permission and without regard to Aboriginal and Torres Strait Islander peoples' rights to participate or not to participate (Cruse, 2001:27). Cruse puts it simply when she states "Many researchers have ridden roughshod over our communities, cultures, practices and beliefs" (Cruse, 2001:27).

Aboriginal and Torres Strait Islander peoples in the 1970s and 1980s began to voice more strongly concerns about research (Langton, 1981; Langford, 1983). In the late 1980s and the 1990s several publications and statements included issues regarding research with and within Aboriginal and Torres Strait Islander communities (Humphrey, 2001:198). One of the more important statements was contained in *The Royal Commission into Deaths in Custody Report* (RCIADIC, 1991), in the form of recommendation number 330. It recommended that action research was the type of research that was likely to be seen as being most appropriate (1991, no.330). RCIADIC also recommended that, a condition of the research should be the active involvement

of Aboriginal and Torres Strait Islander people, the dissemination of the research findings across the community and proposals for further action (1991, no.320). These are key concepts entrenched within all aspects of the CCRE and represent what has been requested by Aboriginal and Torres Strait Islander peoples for some time (Humphrey, 2000, 2001).

Several publications on ethics in Aboriginal and Torres Strait Islander research followed soon after. *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Research* was approved in draft form by the 111th Session of the National Health and Medical Research Council (NHMRC) in Brisbane in 1991. The guidelines focused on consultation; community involvement; and ownership and publication of data (NHMRC, 1991). As these guidelines were only issued as an interim document, the guidelines were never enforceable. The development of Aboriginal and Torres Strait Islander researchers and community control over priority setting and the allocating of funding were not included. The guidelines did not challenge the dominance of non-Indigenous institutions, research approaches or control over the research agenda (Anderson, 1996; Humphrey, 2001). The principal of community control is central to the CCRE and QAIHC as they represent the interests of the community controlled Aboriginal and Torres Strait Islander health service sector in Queensland.

The Aboriginal and Torres Strait Islander Commission (ATSIC) issued its own guidelines on Aboriginal and Torres Strait Islander Research in 1994 which posed the notion of community control. Some Aboriginal and Torres Strait Islander tertiary education centres, research collectives and research units additionally produced documents pertaining to preferred research styles and ethics statements and also began to outline the importance of community control and community involvement (ARI, 1993; Koori Centre, n.d.). The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) produced the Guidelines of Ethical Research in May 2000 (AIATSIS, 2000). The Institute has a research grants program and in this way is able to actively encourage and support ethical research practices within Aboriginal and Torres Strait Islander communities. The AIATSIS Guidelines have assisted in the development of the research guidelines for the CCRE.

Along with the position papers listed in the above paragraphs numerous other works around Aboriginal and Torres Strait Islander research processes and ethics have been written by Aboriginal and Torres Strait Islander writers (Brady, 1992a & b; Gilbert, 1995; Fredericks, 2003; Martin, 2001; Nakata, 1998; Rigney, 1997, 1999, 2001 and others). Humphrey (2000) provided an analysis of research specific to Aboriginal and Torres Strait Islander Australian health and a number of examples of good practice to illustrate what can be done in research with Aboriginal and Torres Strait Islander communities. Cruse offered a working example in the health arena with the Aboriginal Health Research Ethics Committee of South Australia (AHREC) (2001:27).

In 2002 the NHMRC produced *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*. Later in 2003 the NHMRC issued the document mostly commonly referred to as the 'Road Map', the *NHMRC Road Map: A Strategic Framework for improving Aboriginal and Torres Strait Islander Health Through Research*. This document sets out criteria for health and medical research with and of Aboriginal and Torres Strait Islanders which all research proposals and funding applications must address. These include: that research be based on identified need; be action oriented; contain a skills and knowledge transfer strategy; provide proper acknowledgement of and ownership to Aboriginal and Torres Strait Islander peoples; include consultation; Aboriginal and Torres Strait Islander ways of working; and community control of research. These criteria formed the basis of the discussions between the CCRE partners and health services at the CCRE conceptual and proposal phase through to the development of its structure and Research

Program. Aboriginal and Torres Strait Islander people have been engaged at all levels of the CCRE and in all of its activities. The principle of community control is central to this CCRE model. The CCRE model will now be explored.

A Sign of Change: Governance and Community Control of Research

QAIHC leads and governs the newly established NHMRC CCRE. QAIHC is the State peak body for Aboriginal and Torres Strait Islander Community Controlled Health Services in Queensland and is the State Affiliate of the National Aboriginal Community Controlled Health Organisation (NACCHO). QAIHC was established in 1990. Since establishment, the number of Aboriginal and Torres Strait Islander Community Controlled Health Services (AICCHS) in Queensland has grown significantly to 23. QAIHC also has significant partnership arrangements with other health related community controlled sectors in Queensland through the child protection and alcohol and other drug organisations.

The CCRE research program focuses on the prevention and management of circulatory and associated diseases, such as heart and kidney disease, in Aboriginal and Torres Strait Islander peoples living in urban areas. Circulatory and related conditions are one of the major causes of excess morbidity and mortality in Aboriginal and Torres Strait Islander people in Australia. The establishment of the CCRE under the Community Controlled model of governance is unique and presents both opportunities and challenges for innovative partnerships between universities and Aboriginal and Torres Strait Islander community organisations

The governance structure and processes of this NHMRC CCRE is underpinned by the operating values and principles of self-determination and community control. The principle of community control requires that ownership and governance of the CCRE is vested in Aboriginal and Torres Strait Islander people as reflected by the management and research strategies. The key partner institutions include QUT, UQ, JCU, UoW and the NHF, as well as four participating health services. These include TAIHS, Inala Indigenous Health Service, Kambu, and Brisbane AICHS. A CCRE Executive Committee has been established and includes representatives from each partner institution and whose role is to set the strategic direction of the CCRE Research Program. A CCRE Research Advisory Group (RAG) has also been formed whose role comprises technical oversight of the development, implementation and evaluation of the CCRE Research Program.

One of the key milestones of the CCRE Work Plan was the establishment of a dedicated CCRE office and the employment of staff within QAIHC. A transition CCRE Manager and a Senior Research Officer were employed to co-ordinate and establish the operational framework and research beginnings of the CCRE. Since this time, the Manager has now transitioned into the CCRE Director (Leilani Pearce) and the Senior Research Officer position has transitioned into the Research Manager (Bronwyn Fredericks) to better reflect the roles and functions of the CCRE. A Chronic Disease Coordinator (Audrey Deemal) and a Program Coordinator (Dallas Leon) have additionally been appointed. The CCRE and QAIHC, is extremely grateful to Simone Nalatu (CCRE Senior Research Officer) for the hard work and dedication she provided to the CCRE's establishment and to Sanchia Shibasaki for her work in one of the foundation projects. The CEO of QAIHC has overall responsibility for the administration of the CCRE. The CEO is appointed by the Board of QAIHC. The CCRE sits within the structure of QAIHC as another function of QAIHC as outlined in Figure 1.

CCRE Governance

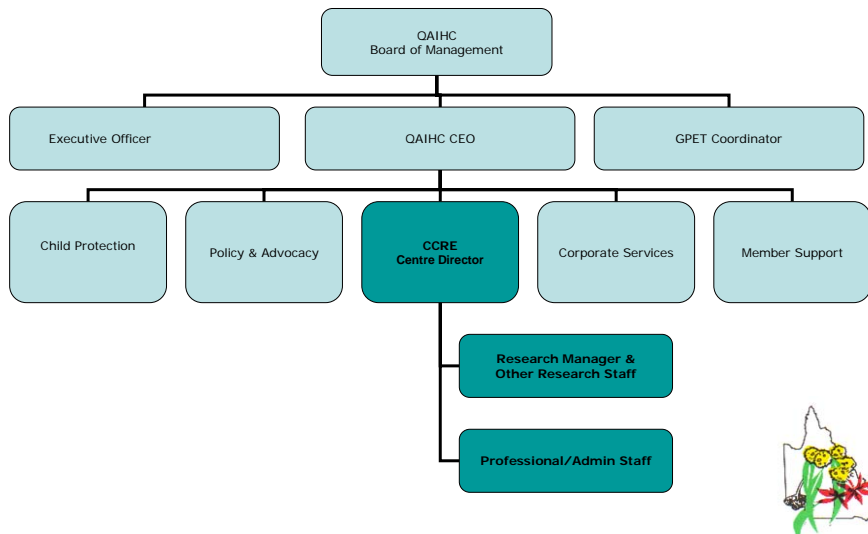


Figure 1. CCRE Governance

Parallel to the formalisation of processes and procedures for the CCRE, has been the incremental development of specific research priorities of each of the four participating health services, that is, the pieces of work that will be undertaken. In order to accomplish this, a series of meeting were organized. First there was a workshop, which was specifically dedicated to the health services and was organised to provide opportunity for health services to voice their concerns, clarify issues and ask questions. The purpose of the meeting was two fold. Firstly the CCRE unit was extremely keen to gain advice from each of the health services about the operational aspects of the Centre – how the projects would be conducted, who would conduct the research, and what were the health services expectations of the CCRE. The second purpose of the workshop was to encourage the health services to collectively start thinking about the pieces of work they wanted undertaken. At the conclusion of the workshop there was a clear indication from each of the health services about the types of work/projects for the CCRE. The health services also had general agreement about those operational aspects of the CCRE that needed to be in place. These operational aspects included – the development of an Information Package, an endorsement process with the respective Health Service Boards of Management within each service, the development of CCRE Research Principles to guide research within the Aboriginal and Torres Strait Islander Health Services Sector.

Second was a joint meeting between the Research Advisory Group and the health services. This was organised in order to inform the Research Advisory Group of the outcomes from the Health Services Workshop, and to then commence discussions to select and prioritise the pieces of work that would be undertaken by the CCRE in the short, medium and long term. This was a significant step in the progression of the Research Program as it provided the Chief Investigators, Associate Investigators and members of the health services, the opportunity to discuss and debate how and when the work would be carried out as well as who would lead the work. At the conclusion of this meeting a document outlining the work to be completed was produced.

Practical health service research, which has full and formal participation and is led by Aboriginal and Torres Strait Islander people, is the platform of the CCRE. The Research Program is being implemented and the Profiling Health Services Project is currently profiling each health service and describing the delivery of chronic disease

prevention and management services and programs within their community. This is in line with what Aboriginal and Torres Strait Islander people within the community controlled health service sector identified as a priority.

The CCRE Research Program

The CCRE Research Program aligns with the NHMRC Roadmap (2003) to improve Aboriginal and Torres Strait Islander health through research with all research conducted under the major thematic areas:

- Descriptive research that outlines the pattern of risk, disease and death as it related to circulatory disease in urban populations
- Identifying points in the life cycle when interventions are likely to be most effective and the life skills and knowledge needed for this
- Health services research that will inform decision-making in relation to practice and funding for health services
- Research that will improve outcomes in relation to circulatory disease in Indigenous communities through other sector initiatives.

The CCRE Research Program has four Program Areas that interconnect with the Roadmap's thematic areas. These are:

1. Improving the prevention and management of circulatory and associated conditions
2. Improving access to health services and programs
3. Health system development and reform
4. Building capacity and enabling health research

Throughout the CCRE development process the partners have had a commitment to working in a way where all participants contribute and benefit. This CCRE model is aligned with community-based participatory action research. In a community-based action research process, the research begins with working with a group, community or organisation in defining the problems, situations, issues and then involves the group, community or organisation in the process of working towards change, finding solutions or answers (Glesne, 1990; Stringer, 1996). Wadsworth, in writing of action research, describes it as 'participatory', that is, people need to participate to make it happen (1997: 61). Participatory research according to Lukabyo, is usually developed with "the purpose of empowering community people to find solutions to community problems" (1995: 4). Participatory action research therefore has the capacity to provide a notion of community development, social justice and empowerment. It can additionally encapsulate elements of political awareness and political action connected to better health if designed this way.

After careful consideration of a range of methods, QAIHC believed that it would be possible to engage several approaches from methodologies known as community-based action research and participatory research (often used inter-changeably). It additionally understood that it needed to incorporate Indigenist research principles as outlined by Rigney (1997, 1999) along with elements of reflexivity and/or introspection. This process has enabled QAIHC to work within an Aboriginal and Torres Strait Islander context engaging both the community controlled health service sector and the higher education sector in the development and implementation of the CCRE. It is recognised that a range of other research frameworks may need to be incorporated from time to time in order to address the research priorities as established by the community controlled health service sector. The challenges for the CCRE and its

partners and staff is to ensure reflection on all proposed research and for clarity on Indigenist research principles, procedures and processes (Martin, 2001; Rigney 1997, 1999).

CCRE Research Principles

The CCRE Research Principles were developed and designed as a guide for researchers wishing to undertake projects and study within the CCRE and the Community Controlled Health Services Sector in Queensland. They are based on the NHMRC Criteria for Health and Medical Research of Aboriginal and Torres Strait Islander Australians, which are:

- Community engagement and participation
- Benefits
- Sustainability and transferability
- Capacity building
- Priority and significance

The CCRE Research Principles require any research project to be based on:

Identified Need – Research projects must be in response to identified community and Health Service needs and priorities. Having the Health Service involved in the development of the full project brief will assist this process as the respective Board of Management needs to endorse any research projects undertaken.

Action Oriented – Research projects must contribute to change within the health service and demonstrate benefit to the community. Outcomes need to be direct and tangible – for example, funding, human resource management, education and training, clinical practice, workforce development and planning, building the evidence base, community development, and capacity building.

Skills / Knowledge Transfer – The methodology of research projects should reflect Aboriginal and Torres Strait Islander people's involvement at all levels of the research project. A clear strategy for knowledge and skills transfer should be an explicit component of any research project. Skills and knowledge transfer strategies should be agreed to with the Health Service at the start of the project.

Acknowledgement – research projects must explicitly recognise the contributions of individuals, community groups, and Health Services in the research process.

Consultation - The research project must have appropriate consultation strategies in place to ensure that the information collected is interpreted in a true and accurate way. Within local Aboriginal and Torres Strait Islander communities and Health Services there are existing processes for consultation and engagement.

These consultation strategies should occur at the critical stages of a research project, including:

- initial engagement in the research project (telling people about the project brief and confirming support for the project)
- agreement on strategies for consultation, information collection, and working with the Health Service and community
- the feedback processes that will be put in place for verification of the information collected

- acknowledgement of the individual(s) and Community Controlled Health Service's involvement in reports, materials, publications etc resulting from the research project.
- agreed mechanisms in place for disseminating information and translating skills and information.

Aboriginal and Torres Strait Islander ownership of information – recognition that information and data collected or related to the Aboriginal and Torres Strait Islander community is owned by the community. Therefore decisions about the way in which this information is to be used and interpretations need to be agreed to by the community.

Aboriginal and Torres Strait Islander Ways of Working – recognition and demonstrable support in the research project for Aboriginal and Torres Strait Islander ways of working as culturally valid and valued in research input, output, and outcomes. This means that there is also recognition of diversity between Aboriginal and Torres Strait Islander people and communities.

Community Control – Community control of health is the fundamental premise on which Aboriginal and Torres Strait Islander Community Controlled Health Services developed. These services are initiated by their local Aboriginal and/or Torres Strait Islander community to provide high quality, culturally appropriate comprehensive primary health care.

Developing a base of Indigenous Health Researchers

The CCRE has as one of its goals to develop a base of Aboriginal and Torres Strait Islander health researchers. The terms 'Aboriginal researcher', 'Torres Strait Islander researcher' and 'Indigenous researcher' brings about a range of labels. It could be assumed that the researchers will work with Aboriginal and Torres Strait Islander people as the objects of research and that the researchers are either Aboriginal or Torres Strait Islander. Both of these assumptions would be correct. However, there are other aspects that also need to be considered. It could be considered that Aboriginal and Torres Strait Islander researchers are both subject and object. What additionally needs to be considered is that many Aboriginal and Torres Strait Islander people who undertake formal academic studies or who have worked within mainstream services previously have been taught how to teach and research using western frameworks and disciplinary methodologies that at times can further colonise and apply imperial measures on Aboriginal and Torres Strait Islander knowledges. The CCRE Aboriginal and Torres Strait Islander researchers will be encouraged to interrogate what we have learnt, look at how we use what we have learnt, how we act, we can assist in perpetuating the negative type of research that has happened within Aboriginal and Torres Strait Islander communities in the past.

Nakata explains that one issue for Aboriginal and Torres Strait Islander scholars is how to speak back to the knowledges that have been formed around what is perceived as Aboriginal and Torres Strait Islander positionings within Western worldviews (1998: 4). Nakata essentially asks 'how do we speak to what is known about us, written about us and not owned by us?' We as Aboriginal and Torres Strait Islander peoples and as Aboriginal and Torres Strait Islander researchers need to challenge what is written about us and what knowledges are controlled about us, otherwise we will continue to perpetuate the untruths and the ways in which we are marginalised and misrepresented / represented.

If we are to bring about change to the way people think about us, know us as Aboriginal and Torres Strait Islander peoples in theoretical, learnt settings, we must be part of these environments. We must challenge the current knowledge bases and ways of acquiring knowledge about us. In this challenging Rigney asserts that we as “Aboriginal researchers who wish to construct, re-discover and/or re-affirm Indigenous knowledges must function in traditions of classical epistemological methods of physical and/or the social human sciences” (1997: 6). Nakata argues that, “In order to understand our position better and to ultimately act to improve it, we must first immerse ourselves in and understand the very systems of thought, ideas and knowledge that have been instrumental in producing our position” (1998, p.4). This is not to say that we need to embrace or fit within the classical epistemological methods of these sciences. We need to know how these sciences are constructed. We need to know how they are used and how they impact upon us, as Indigenous peoples. If we do not, we serve to assist in further colonisation and maintaining our positioning.

Rigney (1997: 2) suggests the employment of Indigenist principles, as a, “step toward assisting Indigenous theorists and practitioners to determine what might be an appropriate response to de-legitimise racist oppression in research and shift to a more empowering and self-determining outcome” (1997: 2). Rigney’s work builds on the scholarship from the work of a number of African-American researchers (for example Asante, 1987; 1988; 1990) who discuss Afrocentric emancipatory methodology while critiquing dominant epistemologies. Asante’s (1987, 1988, 1990) work in particular provides inspiration for viewing and challenging knowledge usage and positionings of marginalised peoples. Rigney (2001) additionally builds on the work of Warrior (1995, 1999) who maintains that Native American intellectual traditions need the freedom to break away from the constraints of the Western academy (1999: 11). In his argument Warrior provides direction that intellectual sovereignty is a process; it is not about outcome (1995: 91). It is about the speaking, reflecting and articulation through a range of means about the Aboriginal and Torres Strait Islander struggle and what strategies to freedom are needed. Rigney in his interpretation of Warrior’s writings outlines that,

If Indigenous intellectual sovereignty is to be emancipatory it must be ‘process driven’ rather than outcome oriented...it is now for Indigenous scholars committed to sovereignty to realise that we too must struggle for intellectual sovereignty and allow for the definition and articulation of what that means to emerge as we critically reflect on our struggle (2001: 10).

In order to bring about the required changes within the knowledges bases, there must be a link between research and the political struggle of our communities. This link needs to be in and through those Aboriginal and Torres Strait Islander Australians who are simultaneously engaged in research and the Aboriginal and Torres Strait Islander struggle. From this understanding, the CCRE and QAIHC are well positioned. As the peak body for Aboriginal and Torres Strait Islander health and the community controlled health services sector, QAIHC is within the day-to-day broader political struggle for improvements in Aboriginal and Torres Strait Islander health. As the CCRE is positioned within and governed by QAIHC and it will increasingly inform and support the work of QAIHC, it is intrinsically linked within this struggle too. It is within this realm that the Aboriginal and Torres Strait Islander health researchers will dwell. The simultaneous linkages and engagement will be in action within QAIHC, the community controlled health service sector and the CCRE. Rigney asserts that “Only in this way can research responsibly serve and inform the political liberation struggle” (1997, p.2). With Rigney’s words in mind, the CCRE is well positioned to research responsibly and to serve and inform the struggle for better health for Aboriginal and Torres Strait Islander peoples.

Conclusion

This paper has outlined the NHMRC CCRE model being lead and governed by the Queensland Aboriginal and Islander Health Council (QAIHC). The establishment of a CCRE under the community controlled model of governance is unique and presents both opportunities and challenges for innovative partnerships between universities and Aboriginal and Torres Strait Islander community organisations and stands in direct opposition to the research of the past. What has been demonstrated is that the CCRE model is reframing Aboriginal and Torres Strait Islander research experiences and extending the principle of community control within the health research domain. The methods and strategies that this CCRE is implementing, is transforming Aboriginal and Torres Strait Islander health research.

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